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Title: The need for culturally competent care within gastroenterology services: Evidence from research with adults of South Asian origin living with inflammatory bowel disease

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Abstract

Background and Aims: It is widely acknowledged that the incidence of inflammatory bowel disease (IBD) is rising within South Asian populations, yet research into the experiences of this group of patients is rare. In this study the lived experiences of UK South Asian adults with IBD, including support from gastroenterology services, was investigated.

Methods: A sample of 33 patients representing the diversity of the UK South Asian population were recruited through 5 gastroenterology clinics in England. In-depth semi-structured interviews were conducted, audio-recorded, transcribed and analysed using the Framework approach.

Results: Although many experiences align with those of the general IBD population, participants believed that South Asian cultures and/or religions can led to additional challenges. These are linked to: family and friend's understanding of IBD; self and family attributions about IBD; stigma surrounding ill health; the taboo of bowel symptoms; managing 'spicy food'; beliefs about food and ill health; roles within the family; living with extended family; the use of complementary and alternative therapies; and visits to family overseas. Religious faith helped many to cope with having IBD, but symptoms could hamper ability to practice faith. Gastroenterology services were viewed positively, but unmet needs were identified, some of which were culturally specific.

Conclusion: Gastroenterology services have an important role to play in helping patients to overcome the challenges they encounter in their everyday life, both by providing individual patients with culturally appropriate care and advice, and via interventions to increase awareness and understanding of IBD within wider South Asian communities.

Keywords: Inflammatory Bowel Disease; South Asian; cultural competence

Introduction

Formerly considered a disease of developed countries [1, 2] latest evidence indicates a worldwide increase in incidence of inflammatory bowel disease (IBD) and particularly within South Asian populations, both those living in South Asia [3] and, even more so, among those living in the UK.[2, 4, 5] Indeed, a recent study reports a higher incidence among some South Asian populations compared to the white British population.[5] Aside from in the USA, little is known about how IBD healthcare differs according to patient ethnicity,[6] but patients from minority groups typically experience poorer health outcomes, with difficulties accessing or using health care identified as a key factor contributing to this.[7-9] Changes in the prevalence of IBD and demography of patients observed in recent years [1, 2, 10] therefore requires a response from gastroenterology services.[6, 11]

In the 1980s, the notion of 'culturally competent' care emerged [12] in response to observations of inequitable access to high quality health care. In essence, it involves clinicians being able to work and communicate effectively with people from cultural backgrounds different to their own[13] and is regarded as a core aspect of patient-centered care.[14-16] Whilst clinical guidance on the management of IBD highlights the importance of a patient-centred approach,[17, 18] the need for culturally appropriate care does not routinely feature. However, the NICE 2019 Crohn's disease (CD) guidelines (https://www.nice.org.uk/guidance/ng129) do recommend that information and advice about the condition meets the cultural and linguistic needs of the local community. However, implementing such guidance is difficult if clinicians have an incomplete understanding of the way ethnicity and culture may affect patients' needs and preferences for care and support. Clinical commentaries are beginning to emerge. For example, a recently published paper by US gastroenterologists expressed concerns that clinicians do not reflect the ethnic profile of their patient population [19] and that this has implications for patient care. There are also a number of examples of guidance notes on stoma care for patients of different faiths.[20-25] Whilst useful in

awareness-raising, such advice is not grounded in research evidence on the lived experience of IBD. Existing evidence on IBD patients' views and experiences rarely includes participants from ethnic minority groups.[26] An exception is a small UK study of young adult IBD patients from minority ethnic communities, with the recruited sample predominantly Muslim male patients and therefore not representative of the wider UK South Asian IBD patient population .[27] It found that lack of understanding of IBD within the patient's immediate family and wider community led to feelings of isolation and inadequacy. For some, isolation was compounded by a desire to avoid gatherings where food with spices was being served. Other studies investigated specific issues including diet, use of complementary medicine, and information needs,[28-30] but all were conducted some years ago and are potentially outdated. Aware of the limitations of existing evidence, and given the rising number of South Asian patients in UK IBD clinics, we undertook a qualitative study to investigate the lived experiences of UK South Asian adults living with IBD. This paper reports our findings and considers their implications for culturally competent care within gastroenterology.

Materials and Methods

Methods are reported in line with COREQ reporting guidelines.[31] The study was approved by an NHS Research Ethics Committee (Ref 13/NE/0034).

Study Aim

The overall aim was to describe the lived experience of UK South Asian adults with IBD, including the support they receive from gastroenterology services, and to understand if and how ethnicity and culture impact on this.

Study Design

A cross-sectional qualitative research design was used, with data collected via in-depth, semi-structured interviews with adult South Asian patients with IBD. The study took an interpretative phenomenological analysis (IPA) approach.[32, 33] This approach is used when the objective is to understand and describe the lived experiences of individuals who share the characteristic or situation under investigation. The analytical stance is largely inductive and it is therefore particularly suited to understanding under-researched perspectives and phenomena.

To overcome known barriers to people with IBD taking part in research[36] and the wider fact that South Asian patients are less likely to be recruited to studies, study participants were able to express preference in terms of interviewer characteristics, including age, personal experience of IBD, gender, ethnicity, language. Further details on this approach are published elsewhere.[37]

Sampling

Qualitative research seeks to ensure that the study sample represents the full range of experiences possible with respect to the issue or topic under investigation[34, 35], rather than generalisability as the term is understood in quantitative studies. We hypothesised the following characteristics may influence the lived experience of IBD and sought to ensure their representation in our sample: age, gender, type of IBD (ulcerative colitis, Crohn's disease), age ethnic group (i.e. Bangladeshi/British Bangladeshi; Indian/British Indian; and Pakistani/British Pakistani) and faith (e.g. Christian, Hindu, Muslim, Sikh). These factors comprised the study's sampling frame, and were the key characteristics by which, at analysis, we sought to compare experiences (Lindsay 2018). Decisions regarding target sample size (n=30-35) were guided by the sampling frame. Within this target, our aim in terms of

country of origin was: India (15), Pakistan (10) and Bangladesh (5). And for religion, Muslim (10), Hindu (10) and Sikh (5).

When interpreting and drawing implications from our data, we compared and located our findings within existing work on the lived experience of IBD by white Americans and Europeans, and other non-South Asian groups (e.g. Mexican American).

Recruitment

Eligibility criteria were:

- confirmed diagnosis of IBD;
- 18 years or older;
- identify as being of South Asian origin (that is, come or descended from a South Asian country, i.e. Bangladesh, India, Pakistan or Sri Lanka).

Five gastroenterology services across England acted as Participant Identification Centres (PICs). They were purposively selected to represent services with small and large proportions of South Asian patients, and therefore different levels of experiences in supporting this patient group. PICS reviewed clinic lists to identify eligible patients. A total of 101 individuals were identified by the PICs and each received a recruitment pack – either during a routine clinic appointment or via post. Recruitment materials were available in Bengali, Gujarati, Hindi, Punjabi, and Urdu. Staff involved in passing on recruitment packs had access to interpreting support. Individuals interested in taking part returned an Expression of Interest (EoI) form direct to the research team. The form also collected information on sampling characteristics and preferences regarding interviewer characteristics.

Forty-one people (40.6%) returned the EoI form. The sampling frame was used to identify individuals (n=32) to take forward to interview. Three declined to participate. Reasons were: family concerns that taking part would be too demanding; current ill-health; believing current good health meant they would have little to contribute.

This primary recruitment strategy (yielding 29 participants) was supplemented by recruiting a further 4 individuals who had directly approached the research team either through membership of the PAG (n=3) or via the project's webpage (n= 1). Using this additional recruitment strategy enabled a more complete representation in the study sample of characteristics set out in the sampling frame.

Data Collection

Participants chose between a face-to-face (n=18) or telephone (n=15) interview. A topic guide was used to ensure consistent and comprehensive coverage of topic areas across all interviews. It was developed through an iterative process of consultation with clinicians and IBD patients. A key forum for this process was the Project Advisory Group.

Interviews explored:

- history of IBD and current health;
- day to management of IBD, and managing flare-ups;
- others' responses to diagnosis, treatment, and self-management;
- impacts of IBD and sources of support;
- using gastroenterology services;

- awareness and use of Crohn's and Colitis UK (research funders) (findings reported elsewhere)

For all the above topic areas, having described their experience, participants were asked to reflect on the extent to which they believed culture, faith, age and gender impacted these experiences. A simple visual aid (translated into all relevant languages) depicting the various life domains (e.g. my work, my relationship with my partner, leisure activities and hobbies etc.) facilitated discussions. Interviews lasted between 30 minutes and three hours. All but one was audio-recorded (with permission) and fully transcribed. Where consent was not given for audio-recording, detailed notes were made during and immediately after the interview. Where interviews were conducted in a South Asian language a written, English translation was generated by the interviewer focusing on conceptual rather than literal equivalence.[38]

Data analysis

A thematic analysis of the data was undertaken guided by the 'Framework' approach [41] , which supports robust and transparent management of data analysis process. Steps involved: data immersion; identification of themes; data reduction; data display; and analytical writing. Given the aims of the research, the focus of the analysis was on identifying and describing the ways that study participants perceived that aspects of their ethnicity (e.g. country of origin, faith, culture/traditions) affected their lived experience of IBD. A process of constant comparison[40] with the accounts of other study participants allowed us to explore and test whether accounts differed within and between ethnic groups, and the influence age and gender on those experiences. The thematic framework used to organise and interrogate the data is available (see Supplementary Figure 1). Supplementary Figure 2 provides a fuller account of the analytical process.

Patient Involvement

The Project Advisory Group (PAG) included seven South Asian IBD patients. We used meetings (n=2), email and telephone conversations to consult with them about the recruitment strategy and materials, interview topic guide, and data analysis and interpretation.

Results

We provide a brief overview of study participants before reporting our findings, which fall into three broad domains: the lived experience; the benefits and challenges of practising faith; and experiences of using gastroenterology services. Verbatim quotes are used to illustrate findings. To preserve anonymity, quotes are only identified by study ID, gender and age range.

Study participants

A total of thirty-three individuals (20 women, 13 men), aged 18 to 65 years, took part in the study. The sample reflected the ethnic diversity, and most common faith groups, found within the UK South Asian population[42]. Nineteen participants were born in the UK; the majority of the remainder were born in India, Pakistan or Bangladesh. Duration of diagnosis ranged from three months to 21 years (median six years). Eighteen had Crohn's disease, fourteen had ulcerative colitis; and one had indeterminate colitis. For further details see Table 1-3

The lived experience

In this section participants' experiences in living with IBD are reported. This is divided into two parts. First, experiences shared with the wider IBD patient population. Second, experiences

which interviewees believed were due to, or intensified or exacerbated by, aspects of South Asian culture and religions.

Experiences shared with the wider IBD patient population

In line with research on the wider IBD patient population[26, 43, 44] participants described how IBD symptoms caused challenges in many aspects of their everyday life, often recognising that these experiences were shared by IBD patients whatever their ethnicity.

> '*I don't think it makes much difference whether you're Sikh or Indian or English or anything. Pain is pain at the end of the day'.* [ID 8, Female, age group 45-65 years]

All reported that flare ups were painful and exhausting. These symptoms, coupled with the need for frequent trips to the toilet, meant many described themselves as being housebound when flare ups occurred. In between, ongoing milder symptoms were reported. The majority of participants adhered to prescribed medication and used a range of strategies to manage or control symptoms such as excluding certain foods or limiting the amount they ate, lifestyle adjustments (e.g. changing job, slower paced life and exercise) and the use of complementary and alternative medicine. Immediate family were often a source of practical and emotional support. However, support from extended family was typically more limited due to geographical distance or them having caring, or other, responsibilities.

Despite the efforts made to manage their condition, and the support received from others, the negative impact of having IBD on emotional well-being was a dominant theme in interviewees' accounts. Feeling low, depressed or anxious added further to the difficulties people experienced so

that, even when symptom free, some curtailed their activities due to loss of interest or worries about the possibility of experiencing symptoms.

> *' "We've just left the house ten minutes ago, why couldn't you have gone then?" "I didn't need to go then, now I need to go .." And then I'm in a panic even more because I think oh I'm not going to get to the toilet on the journey there .. so that makes me want to go even more. It might not be a flare up, I think it's sort of probably psychological half the time'.* [ID1, Female, age group 25-44 years]

The combination of physical symptoms and emotional difficulties meant individuals struggled at times to maintain a social life, manage study, work and/or caring responsibilities, and/or relationships with partners. A few also reported financial difficulties. A very small minority spoke of times of intense despair and wanting to 'give up'.

The impact of South Asian culture and religions on lived experiences

Analysis of the data revealed eleven ways in which South Asian cultures and religions were identified by study participants as influencing the lived experience of IBD.

Family and community members' understanding of IBD

Most participants felt they had a good understanding of IBD, often attributed to the advice and information provided by IBD clinic staff, but also linked to their own endeavours to seek out information. However, many reported family members – close or extended – misunderstood IBD. For some this remained an unresolved issue. A number of ethnicity-relevant factors were identified as contributing to this. First, the diagnostic label 'Crohn's' may not have been assimilated into a

South Asian language. Second, the term 'inflammatory bowel disease' could cause confusion as the word 'disease' may hold different connotations in South Asian countries; for example, denoting infectious and/or life-threatening conditions.

> *'The first day I told my husband he was gobsmacked because he's never heard of having a disease where you don't end up dying'.* [ID 10, Female, age group 25-44 years]

Interviewees believed these linguistic issues were compounded by the fact that, compared to the UK, IBD is less prevalent in South Asia and therefore less likely to have been encountered by family members and others in their social networks and communities.

> *'Of course they have no understanding about the Crohn's, even abroad as well. All they know is about TB, or... they have infection, or ulcers. But Crohn's is something unfamiliar abroad. What is Crohn's? But this is not a name abroad. In the UK they have given it Crohn's or colitis. But abroad is, this thing is totally unfamiliar, they have not given this name'.* [ID 23, Male, age group 25-44 years].

Self and family members' attributions of IBD

A sub-sample (all Muslim men) described beliefs – held by themselves and/or their families – which attributed the cause of IBD to past actions (e.g. sex outside marriage, drinking alcohol, eating 'junk food') thus generating a sense of self-blame. Beliefs about the cause of IBD being due to lifestyle were occasionally spoken of in combination with views on what it was to be a 'good Muslim'. For example, one participant spoke of how perhaps if he had been a "better Muslim" and not been so "financially greedy", leading him to work long hours, he would not have developed the condition.

The stigma of ill-health

Most participants spoke of being reluctant to reveal to others in their community that they had IBD. They believed that ill health is particularly stigmatised in South Asian communities especially, but not exclusively, within more traditional communities or among older members. They evidenced this by describing the way that, in their communities, having a health condition impacts on 'marriageability', of both of men and women, something partly fuelled by concerns about the health of future offspring.

> *'So I think, yeah, people tend not to talk about, you know not only IBD but like if they have any illness in general....* [in] *the Asian community arranged marriage is still prevalent. So if you were, wanted to do that and you said you've got this [IBD] then .. people,* [the] *opposite party, is less likely .. going to want to marry you…I think they also look for …they don't want it to seem like you've got bad genes or anything cos then you could pass it down to your children or whatever'.*
>
> [ID 30, Male, age group 25-44 years]

Taboo around bowel symptoms

Whilst participants acknowledged that talking about IBD symptoms (particularly bowel-related) might be embarrassing for anyone, a number believed this subject was particularly taboo within South Asian communities.

> *'*[in Pakistan*] it was awful, like they just, it's just not something they speak about. Even when I went to see the doctor, I just did not feel comfortable telling him about my bowel movements, whereas when I go to the doctors here* [UK] *it's fine. But I really did not feel*

comfortable at all discussing my bowel movements there, with him or actually, any other Asians really. Whereas over here it's, it's more acceptable I think to discuss'. [ID 34, Female, age group 18-24 years]

It is important to note at this point that the different issues described above, all of which impacted on communication and support from family and wider social networks, were often identified as being interconnected and simultaneously affected participants' sense of isolation and a desire not to disclose their diagnosis.

'I haven't told my brothers and sisters or anyone. I just feel like it's embarrassing for me and I just feel like, you know, to tell someone that you, you've got a disease .. just like the reaction I had at the beginning, "oh it's something that's catchy", "it's something that you may end up dying". I don't want no-one to feel like that, I don't want people to start treating me differently'. [ID 10, Female, age group25-44 years]

"Spicy food" and food as a key element of social gatherings

Most participants had found, or believed, food with spices exacerbated IBD symptoms and preferred to avoid it. This could mean eating, or preferring to eat, different food to other members of the household. This was manageable when they were responsible for family meals and cooking, but more difficult if they were not; for example, young people living with parents, women living with husband's family. A reluctance to eat, or avoidance of, food with spices also became an issue at social occasions, particularly when participants had chosen not to tell others they had IBD. Some dealt with this by avoiding such events or staying for a short period of time so as to avoid eating. Negotiating non-attendance when unwell was made more difficult in situations where the individual had chosen not to tell those outside the close family about their condition. Some study participants

reported that the difficulty of refusing food, or social pressure to eat, either in or outside the home, meant that they ate foods despite believing they would make them unwell.

> *Or even at home if my mum's made something and I find it, if I tell her I, I find it quite spicy, she just thinks that, you know, it's just me being funny because everybody else is fine with it, and then, because of that sometimes you just carry on eating.'*
>
> [ID 34, Female, age group 18-24 years]

Beliefs about the links between food and health

In addition to the complexities of avoiding food with spices, some participants spoke of difficulties getting others to accept the diet they had chosen to follow because of cultural and religious beliefs about food which may be held by family members and the wider community. Two types of beliefs were referred to. First, the belief that health problems are the result of an 'imbalance' in the foods a person eats, resulting in the perception that IBD could be cured through a change of diet. Second, within some faiths, beliefs that certain foods are blessed and therefore cannot be harmful, or exacerbate, symptoms.

> ***'**I think the biggest problem will be some people will not be able to differentiate from their religion to medicine. They just can't seem to see why this food is breathtakingly bad for me.**'***
> (ID 18, Male, age group 25-44 years)

Expectations regarding roles within the family

Societal norms and expectations in many cultures means women with IBD, in particular, may be concerned about its impact on their ability to manage childcare and housework[45], especially during a flare up. Evidence from this study indicates that this may be a particular issue, and more acutely

felt, by women of certain ethnicities. Thus, female study participants from more than one faith group, and including both women born in the UK and those who moved to the UK, described concerns about the *social consequences* of not being able to fulfil these roles, feeling that they may not be "forgiven" by others in their community or regarded as a failure.

> *I mean if people, my family or anyone, find out that my husband's helping with cooking and cleaning, not everyone's going to be happy about it, everyone's going to say, "Well, what's the wife there for? The husband has to go to work, has to cook, has to clean, get the children from school and everything, what's all that about, you know, what's the wife doing?". It's really hard to explain to people that when you're unwell, you're unwell'.* [ID 12, Female, age group 25-44 years]

An additional issue related to this, and either experienced or anticipated by females across a range of ages and at different life stages (i.e. single, newly married and married for a number of years), were concerns about conceiving. It was clear from these participants' accounts that an unwillingness to talk to others about having IBD exacerbated the strain and distress experienced:

> *'If I'm honest, there's just that big burden in your head that, you know, I get the pressure in our culture just to say why aren't I getting pregnant again, that's, that's one of the big pressures that I get….. but you can't go around telling everybody I've got Crohn's disease, I'm unwell, do you know, that's why I'm not getting pregnant maybe as quick as a normal person will'.* [ID 12, Female, age group 25-44 years]

Male participants also described feeling under pressure to meet culturally prescribed obligations (e.g. providing for family) which the impacts of IBD sometimes rendered difficult or impossible to fulfil. This could lead to internal conflicts and a sense of failure.

Living with extended family

A number of participants lived with extended family and most described them as supportive. However, some women described being embarrassed about their IBD symptoms when they first moved into their husband's family home and, as previously mentioned, it could be difficult to adhere to their preferred diet. Participants also pointed out that living in larger households could reduce easy access to toilet facilities**.**

The place of complementary and alternative medicines

Many participants used complementary and alternative medicines (CAMs). Although many people with IBD choose to use CAMs,[46] it is important to note that some of the CAMs mentioned were traditional Indian medicines or remedies (e.g. Ayurvedic medicine, isabgol). A few spoke of seeking out, or planning to seek out, CAMs when they had visited family in South Asian countries. Some described being encouraged to seek them out by family members.

Most participants did not know the ingredients of homeopathic or herbal remedies which they used and typically believed that CAMs could not do any harm as they were 'natural' or herbal'. However, a few had suffered side effects and described being surprised to learn from their IBD specialist nurse that some herbal remedies should not be taken alongside IBD medications. Others choose not to use CAMs; reasons for this included acting on the advice of family members who were health professionals and witnessing ill-effects of CAMs on a family member seeking to manage another health condition.

> *'I just feel like the doctors are in their places for a reason, the consultants are there in their places for a reason, we should just leave these things up to the professionals'.*
>
> [ID 10, Female, age group 25-44 years]

The place of faith healers

A few participants had consulted a faith healer, not always someone from their own faith. In all cases, faith healers had been used in addition to, not instead of, NHS treatment. A couple of participants referred to pressure from one or more family members to seek help from a faith healer. In both instances, this had been resisted.

Visits to family living overseas

Most participants made trips overseas to visit relatives, often for extended periods of time. Many worried about travelling, particularly the likelihood of restricted access to toilets when flying or on car journeys. Furthermore, staying, or anticipating staying, overseas generated worries (which were sometime realised) about having to seek out medical care from health practitioners unfamiliar with IBD, managing a gastro-intestinal infection, safe storage of their medication, and disposing of stoma pouches. Some had experienced (sometimes very acute) flare ups, which they attributed to not adhering to medication, not realising how medication needed to be stored, or changes to diet. It is important to note, however, that despite these concerns, and to their surprise, some participants described finding their health improved during such trips. They speculated as to why this might be, most commonly attributing it to the warmer climate, good diet and being looked after by family.

The benefits and challenges of practising faith

Participants across all faiths spoke of how their faith helped them to cope with having IBD, particularly with pain. A number described the calming, almost meditative, effect of prayer, and the benefit of being active within their faith community since such roles and responsibilities provided a

443 reason to overcome difficulties caused by IBD. Among those who fasted, a few people commented
444 on experiencing reduced IBD symptoms after fasting.

445

446 Within our sample, it was the Muslim interviewees where faith was most likely to emerge as an
447 important feature of their lived experience of IBD. For example, they particularly referred to the
448 belief that having IBD was God or Allah's 'will', explaining that this helped them to re-construct IBD
449 not as a problem, but as a challenge sent by God, to which they needed to accept and respond.

450 *'It would be easy to say "Why me?", but being Muslim everything is seen as a test. The*
451 *question is "How are you going to deal with it?" …. The prophet was closer to God*
452 *when ill and so I may be too. This is my destiny. If I didn't have Crohn's I wouldn't be*
453 *as understanding of people as I am. Also, this life is temporary, which helps. What*
454 *doesn't kill me makes me stronger. Also prayer helps to calm me down. This hospital*
455 *Imam was also very helpful. He would try to give me a pep talk. Help me to see things*
456 *in a positive way.* [ID 31, Female, age group 18-24 years]

457

458 At the same time, a common theme among Muslim interviewees was how IBD affected their ability
459 to practice or fulfil religious rituals and requirements, and the impact this had on them. There were a
460 number of dimensions to this: physical demands of rituals, confinement to home, and social
461 embarrassment First, daily prayers (Salat[1]), taking place five times a day could be challenging, if not
462 impossible, to fulfil when experiencing pain and fatigue. In addition, the requirement for ritual
463 washing prior to praying (Wudu [2]) could be additionally demanding during flare-ups because it may

[1] **Salat** is the practice of ritualistic prayer in Islam. It is usually performed five times a day and preceded by ritual ablution. It consists of the repetition of a unit called a*rakʿah* (pl. *rakaʿāt*) consisting of prescribed actions and words.
[2] **Wudu** - Before conducting salat, a Muslim has to perform a ritual ablution. Wudu is performed using water (*wudu*) and involves washing the hands, mouth, nose, arms, face, hair (often washing the hair is merely drawing the already wet hands from the fringe to the nape of the neck), ears, and feet three

need to be performed more than usual as it is nullified by natural discharges and therefore has to be repeated should that occur. Second, and as a result, leaving home could be difficult, or was avoided, due to difficulties finding bathrooms with the appropriate washing facilities.

> *'When you* [someone who is not South Asian] *would have to go to the bathroom, you would just go to the bathroom. When I'm outside* [the home] *I have to go to the bathroom where there's like maybe water facilities or I'll take a bottle or something with me. We clean ourself in a different way, because of our religion, so that would be a big issue for me. When I first got Crohn's and I was suffering from diarrhoea it put a lot of fear on me. .. So yeah, it would probably prevent me going out for long periods of time'.* [ID 3, Female, age group 25-44 years]

Third, Muslim men in our sample described being worried about attending their Mosque for prayers due to the possibility they would pass wind. Despite these difficulties some said they endeavoured to pray as much as possible, even when unwell, since not doing so led to feelings of guilt. Others described praying more when they were well to 'make up' for missed prayer caused by an exacerbation of symptoms.

Experiences of using gastroenterology services

With just a few exceptions, participants described their overall experiences of care and support from their gastroenterology services in positive terms. They appreciated the ease of access to the team outside of scheduled appointments, felt comfortable talking to staff about sensitive issues, and valued the information provided. Where shortcomings were identified, and in line with findings

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times each in that order. It is not obligatory to wash the hair three times, once is sufficient, and men must also wash their beard and moustache when washing the face.

from research with other IBD populations,[47-49] there was disappointment that the focus of consultations was purely on medical management of the condition, with staff not having or taking the time to discuss how they were coping with the condition.

> *'They ask the question of what symptoms am I getting with my Crohn's where I can just waffle on and just say "Oh I've got diarrhoea" etc., etc. But it's not, the question's not there as to saying like "what are you finding difficulty with, how are you living at home or have you got someone supporting you at home?"* [ID 10, Female, age group 25-44 years]

In a small number of cases, participants spoke of significant mental health difficulties (i.e. depression, panic attacks, and suicide attempts) which they ascribed to having IBD. None had discussed these issues with their gastroenterology team, feeling it was not part of their remit. Some participants spoke positively about culturally sensitive support from their clinical team. Examples included consultants taking time to help prepare people for trips overseas and being given advice about the increased risk to South Asian patients of vitamin D deficiency. Others, however, reported experiences which suggested deficiencies in culturally competent care. Thus, participants, typically women, referred to staff not appreciating the importance to (some) South Asian patients of being able to fulfil cultural expectations around what constitutes a 'good' wife or mother, and the need to find treatments and/or strategies which enabled them to take on these roles. As one woman explained:

> *'I'm just now with the issue with the pregnancy and stuff, cos obviously I've been pushing it towards them saying, like it's important that I need to get pregnant and they don't understand. ... it's a big stress thing for me in the fact that I'm not getting pregnant and I want to get pregnant.'* [ID 10, Female, age group 25-44 years]

Others reported unmet needs in terms of dietary advice tailored to South Asian diet. Finally, among those using, or interested in using, CAMs, a number had chosen not to discuss this with the clinical

team feeling that they were not interested in, or 'negative' about, such treatments.

Whilst not directly relevant to the majority of our interviewees, a general awareness of a lack of adequate translation services was sometimes raised in interviews. Two participants did require such support and the potential stress caused by lack of access to an interpreter is apparent in the following quote:

> *'I can't speak English with the white doctors. Sometimes an interpreter is at the appointment but for the past 3 or 4 appointments no one was booked…… Sometimes the hospital tells me to wait for the interpreter. I have waited a couple of times but if I wait then where do I leave the kids?..... The hospital should be aware of these issues and make allowances in how they allocate appointments. Yes, I am ill and so I should wait, but I can't do this all the time'.* [ID 13, Female, age group 25-44 years]

Overall, it was the two individuals requiring translation services who appeared most dissatisfied with their care and the difficulties they reported (i.e. inadequate explanations for their disease, lack of dietary advice, poor communication of results) could, at least in part, be attributed poor access to translation services.

Discussion

As is reported by studies of other IBD populations,[26, 43, 44] participants in this study – all South Asian patients with IBD - described the challenges of living with pain, the unpredictable (and sometimes uncontrollable) nature of IBD symptoms, and the effect these both had on their emotional well-being. Similarly, they also described the wide-ranging impacts IBD could have on their lives (i.e. work/study, caring responsibilities, social life and/or relationships with partners). In addition, this study has also identified ways that South Asian culture and religions may affect the lived experience of IBD. This carries implications for clinical care and practice. Before turning to these, we summarise and reflect on the study's findings, locating them where possible in the context of existing evidence.

First, participants believed that South Asian patients with IBD may be more likely to conceal their condition and experience a greater sense of isolation. This was attributed to poorer understandings of IBD within South Asian communities due to its relatively low incidence in South Asia. In addition, ill-health and bowel-related symptoms were regarded as carrying greater social stigma and had the potential to further contribute to feelings of isolation, failure and shame. A subsequent, smaller UK study of South Asian women [50] with IBD reports similar issues. Whilst not uniquely faced by South Asian patients,[51] study participants believed a lack of awareness and understanding, and issues of stigma, are more likely to be encountered, or exert a greater impact on, the lives of South Asian patients compared to other patient groups.

A second aspect of South Asian culture which participants believed impacted on their experiences of living with IBD was that they were part of a culture where eating food with spices is the norm. Yet, spices were believed to exacerbate IBD symptoms. As a result, and also reported elsewhere,[27] many preferred to avoid such foods, but managing this inside and outside of the home could be

554 challenging and a source of considerable anxiety. Our study adds further to our understanding of
555 the difficulties South Asian patients may have in adhering to their preferred diet. Specifically,
556 cultural or religious beliefs about food (e.g. foods being blessed or beneficial to health) may mean
557 individuals feel under pressure to eat foods which, they believe, exacerbate symptoms.

558

559 Third, the impact of IBD on ability to fulfil gender-role expectations was a significant concern for
560 some participants, most often woman. Such roles are universal and may affect anyone's lived
561 experience of IBD.[45] However, interviewees believed that the potential social consequences of an
562 inability to fulfil these roles were greater in South Asian communities. Such expectations resulted in
563 participants experiencing an additional pressure to present themselves as managing when they were
564 not.

565

566 A fourth issue concerns the use of CAMs. It is well-documented that many people with IBD use
567 CAMs.[46, 52, 53] It was therefore not unexpected to hear about their use in this study. As with other
568 IBD patient groups,[53] there was a reluctance to discuss CAMs with clinical teams due to perceiving
569 them as disapproving of, or being uninterested in, alternatives to medical treatment. The additional
570 complexity with respect to patients of South Asian origin is that some reported sourcing, or planning
571 to source, CAMs when making visits to relatives in South Asian countries.

572

573 In addition, a small minority of our sample described experiences of being pressured by relatives to
574 use a faith healer. The use of faith healers is not unique to patients of South Asian origin, and can be
575 experienced as helpful.[54, 55] However, our finding that patients may not be voluntarily seeking it is
576 concerning. It is not clear from the existing literature whether South Asian IBD patients are at
577 increased risk of this compared to other patient groups.

A fifth aspect of South Asian ethnicity salient to the lived experience of IBD was religious faith. In line with wider evidence on living with chronic conditions,[56] for some their faith was highly relevant to their lived experience of IBD. It helped participants to make sense of their illness and motivated them to strive to manage and overcome difficulties. Rituals and other practices (prayer, fasting) were described as being beneficial but also as an additional challenge. At the same time, adhering to religious requirements of some South Asian religions (e.g. washing after bowel movements), the frequency (e.g. number of prayer times each day) and physical demands of rituals (e.g. kneeling, prostrating) could become very challenging during flare-ups and, if not adhered to, became a further source of distress. The latter emerged as particularly salient to Muslim men in our sample.

Finally, it is known that travel can be challenging for IBD patients,[57, 58] this is the first study to shed light on the implications for IBD patients of making extended visits to friends and relatives in their countries of origin. Many described anticipating and undergoing the travelling to be very stressful. Whilst there, some experienced, often unexpected, improvements in their health. However, others described experiences of deteriorations in health, difficulties adhering to treatment regimes, and an exacerbation of symptoms all of which were difficult to manage.

In summary, findings from our study suggest that, stemming from their culture, ethnicities and faiths, South Asian patients *may* experience IBD in ways different to other ethnic groups. The limited existing evidence on the lived experience of IBD across different ethnic groups means we cannot be sure if some of the issues we identified (e.g. diet, social expectations, mis-understandings of IBD) are *unique* to South Asian communities. However, we do know that existing research (predominantly with white Americans/Europeans) has not identified these issues, or has not found them to exert a significant impact on people's lives and/or their ability to manage their condition.

Implications for patient care

This study has identified aspects of South Asian's patients' lives which may affect treatment concordance, self-management strategies, emotional support needs, and information and support needs. However, it is crucial these findings are understood within the construct of culturally competent care. This stresses that, as with many socio-demographic characteristics, assumptions should not be made about the ways a patient's ethnicity may affect clinical management and patient care. Rather, clinicians should be mindful that ethnicity may affect managing and living with a health condition, and to look to evidence from individual patients as to what those impacts are. Based on the study findings and the wider evidence base, we suggest a number of responses.

- Gastroenterology services should seek to integrate cultural competence into professional development strategies, and note that existing evidence points to a multi-component approach including training and mentoring/supervision.[59, 60]

- Clinical teams should be mindful that patients may be living in families or communities where IBD is unknown and the symptoms of the condition are particularly taboo, increasing the sense of isolation and rendering the psychosocial support received from the clinical team particularly important.

- Clinicians should be aware that concerns common to the general IBD population (e.g. limited public awareness/understanding of IBD, fertility, ability to fulfil work or caring responsibilities) may carry additional significance and increase the stresses associated with living with IBD. Contacts with the clinical team should create opportunities for patients to explore these and other concerns.

- Information resources for family members, translated into relevant languages and co-created with patients, on the aetiology, symptoms, treatment options, self-management strategies (e.g. pacing/preserving energy, food avoidance) and impacts of IBD should be made available.

- Discussions with patients about diet/dietary advice should:
    - recognise that patients may be concerned about food with spices
    - recognise that cultural beliefs about food, and the key place of food at social gatherings, may make food avoidance difficult and cause anxiety.
    - be aware that patients may have limited influence on food served in the home
    - include the offer of a consultation/information resource for family members regarding food avoidance as a core IBD self-management strategy

- Clinics should identify strategies to consistently convey an openness to discussing CAMs with patients and seek a constructive approach in such discussions;

- Patients should routinely be made aware that it is advisable to consult with their clinical team when planning for extended visits abroad. Clinics should seek to advise on: identification of specialist services/clinicians in destination country or, if unavailable, agreed strategy to manage flare-up or loss/insufficient supply of medication; medication storage requirements; vaccinations and travel insurance. In addition, clinics should provide patients with a written summary of the patient's diagnosis and treatment plan should they need to seek medical attention.

- Clinical teams should consider engaging in proactive work to raise awareness and understanding within local South Asian communities, drawing on experiences from other health conditions regarding collaborative approaches with community leaders and groups.

- Patients should have access to high quality interpreting support during clinic appointments and when virtual contacts with the team are being sought.

Study limitations

Despite known barriers to recruiting UK South Asian patients to healthcare research [61] the study achieved its target sample. Indeed, this is the largest study of the lived experience of IBD among any patient group.[26, 44] Nonetheless, overall response rate was low and it is possible that this resulted in selection bias, something we cannot fully establish as the study design did not include collecting information on non-responders. However, we note that, in line with the vast majority of qualitative studies investigating the experience of living with IBD,[44] more women than men were recruited to the study. In addition, we did not recruit anyone over 65 years of age and the majority of our sample were also fluent in or confidently used English. Whilst gastroenterology staff assisting with recruitment reported that this reflected the language skills of their wider IBD clinic populations, it does remain a limitation of this study.

Conclusions

South Asian culture and religions have the potential to influence the impact that IBD has on patients' everyday lives and how they manage their condition. To some extent, the degree of influence depends on whether the patient lives by South Asian cultural norms and values and within a South Asian community. While some influences, such as the use of faith and religious practice to cope with IBD, had a positive impact, others were negative, creating concerns and pressures which may not be

experienced by other ethnic groups. Findings carry a number of implications for patient care and also point to the need for gastroenterology services to reach out into South Asian communities with awareness raising and educational interventions.

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Conflict of Interest

The corresponding author confirms on behalf of all the authors that there are no conflicts of interest which might bias the research reported or the opinions stated in this paper in any way.

Author Contributions SM led the data collection and analysis reported, and led writing and revising the manuscript. BB provided supervision to SM and contributed to writing and revisions.

All authors were involved in: conception and design of study; made critical revisions to the article; and provided final approval prior to submission.

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Table 1: Country of birth of study sample

Country of birth	Number
UK	19
India	4
Pakistan	4
Kenya	2
Uganda	2
Bangladesh	2

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Table 2: Ethnic group of study sample

Ethnic group	Number
Indian/British Indian	19
Pakistani/British Pakistani	9
Bangladeshi/British Bangladeshi	4
British Punjabi	1

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Table3: Gender, age and religious affiliation of sample

	Age	Muslim	Hindu	Sikh	Other	Sub-total
Male	18-24 yrs	2	0	0	0	2
	25-44 yrs	3	1	2	0	6
	45-65 yrs	2	1	2	0	5
Sub-total		7	2	4	0	13
	Age	Muslim	Hindu	Sikh	Other	Sub-total
Female	18-24 yrs	2	3	0	0	5
	25-44 yrs	5	3	2	0	10
	45-65 yrs	2	1	1	1	6
Sub-total		9	7	3	1	20
Grand total		16	9	7	1	33

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866 **Supplementary Figure 1: Thematic framework for analysis**

Theme 1 – Living with IBD **Codes:** • Getting diagnosed • Symptoms • Strategies for dealing with symptoms & any barriers to using them • Impact on life (positive or negative) • Emotional well-being • Outlook on life • Articulated support needs
Theme 2 – Access to support **Codes:** • Support in household: • Support from outside household • Support from health services
Theme 3 – Perceptions and beliefs about cause of IBD **Codes** • Cause – unclear to participant • Cause - anxiety/stress • Cause - lifestyle • Cause - diet • Cause - punishment • Cause - God/Allah's will
Theme 4 - Visits to South Asian countries **Codes** • Purpose of visit • Impact of visit on health • Adjustments made to medical treatment when abroad • Seeking further/alternative treatment when abroad • Barriers to getting support/treatment when abroad • Articulated support needs
Theme 5 - Feedback & recommendations to Crohn's and Colitis UK **Codes** • Awareness of organisation • Helpful support • Unhelpful support • Ways in which support could be developed – generic • Ways in which support could be developed – for South Asian patients

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873 **Supplementary Figure 2: Detailed account of the data analysis**

To start, the lead researcher (A1) read all transcripts and field notes, with other members of the team (A2, A3) each reading a sub-set. Next, 1-2 page summary, or a 'pen portrait' (Holloway and Jefferson, 2000), of each interview was prepared. These activities supported and informed the identification of themes and the development of an initial thematic framework (led by A1).
This was critically discussed and further developed through a day workshop with the Project Interviewers and at a PAG meeting. A1 then used the revised version to code a sub-sample of interviews. This work was reviewed by A2, resulting in some final fine-grained refinements (Supplementary Figure 1 provides the final version). Data was then coded and extracted by A1 onto a series of Excel (2010) charts (one per theme, with columns used to organise into sub-themes). On each chart, each participant's data was contained in a single row. Extracted data comprised summaries of coded text and, where appropriate, short sections of verbatim text (or quotes). All chart entries were indexed back to the transcript by page number.
Led by A1, but involving the whole research team, charts were explored and interrogated, with iterations of analytical notes being used to describe emerging findings, set out and test the evidence for initial conclusions.
Throughout the data was carefully explored for the impact of gender, faith, country of birth and age on lived experience. All members of the research team were involved in contributing to and commenting on drafts of the report findings.

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